Exploring Asthma Patients' Experience on Medication Adherence
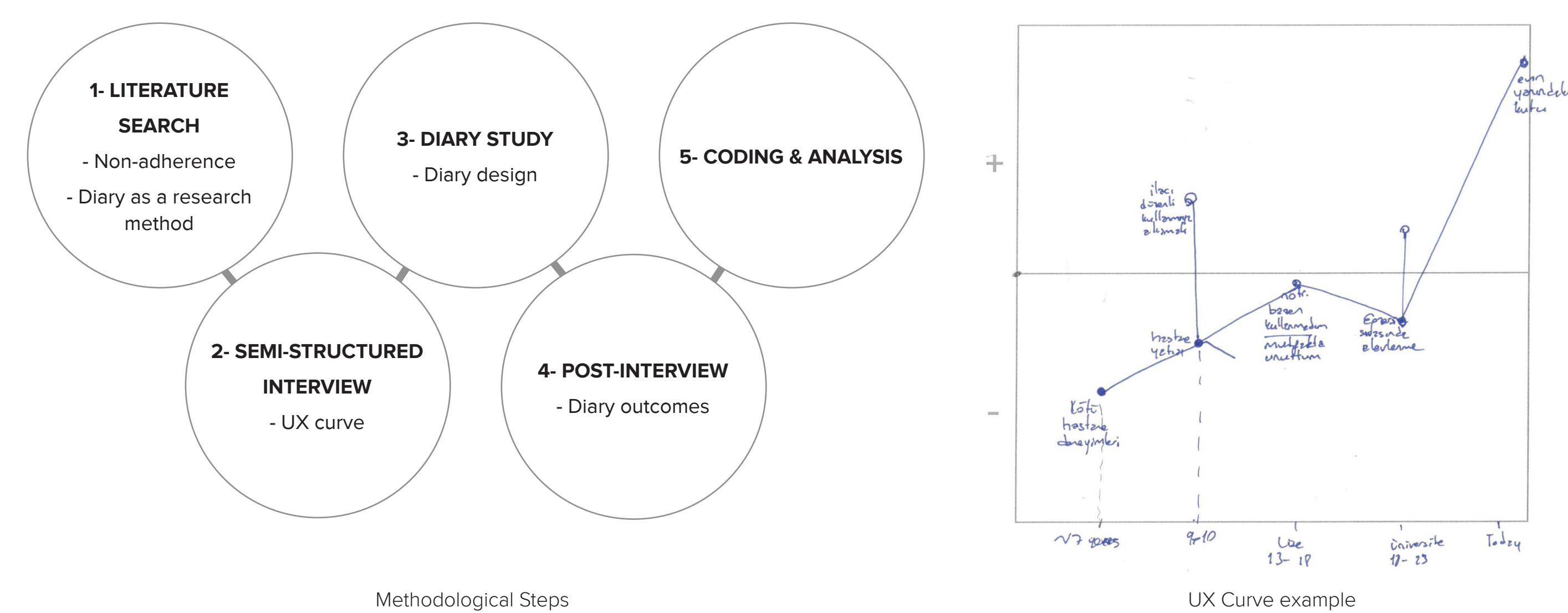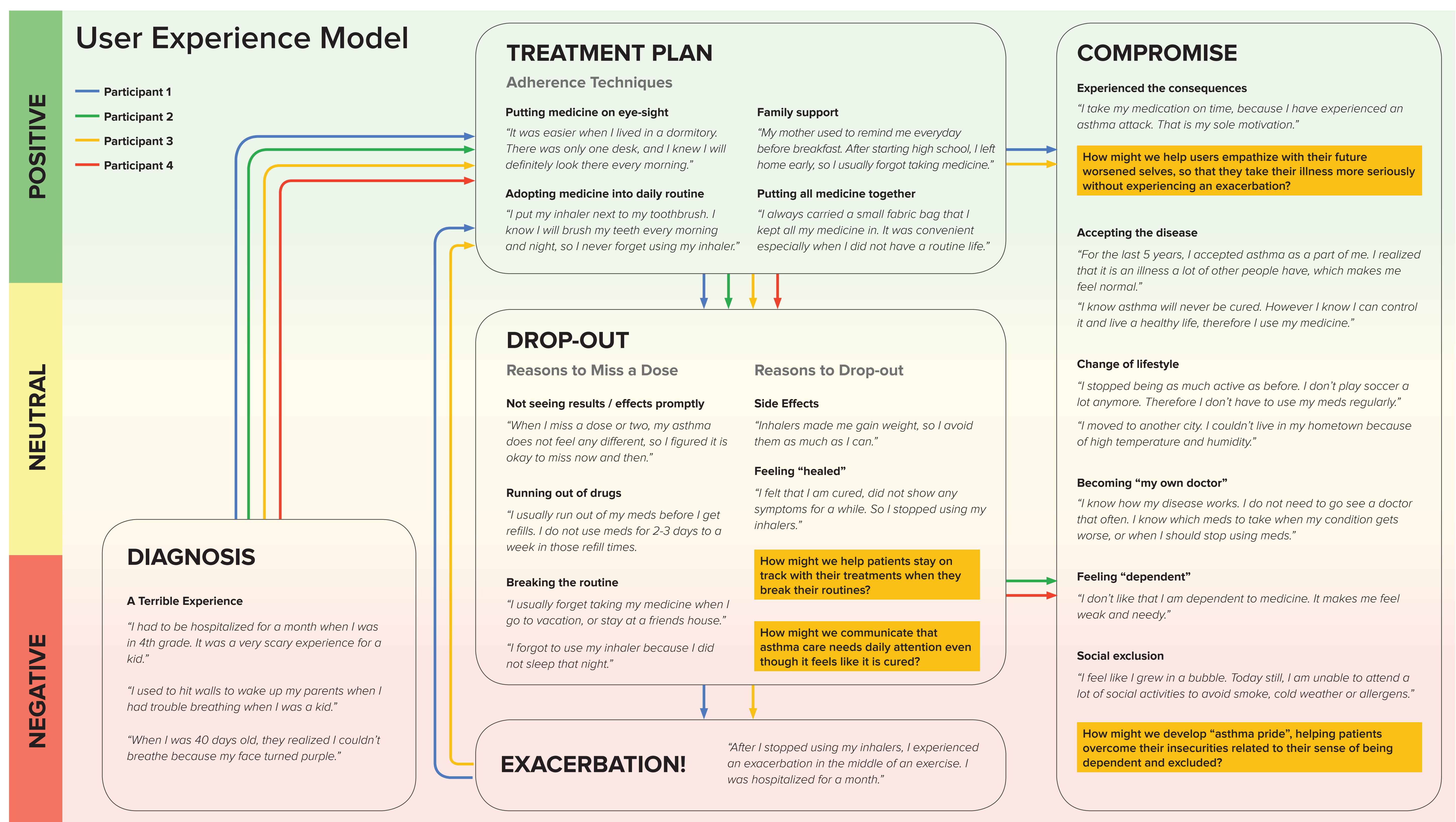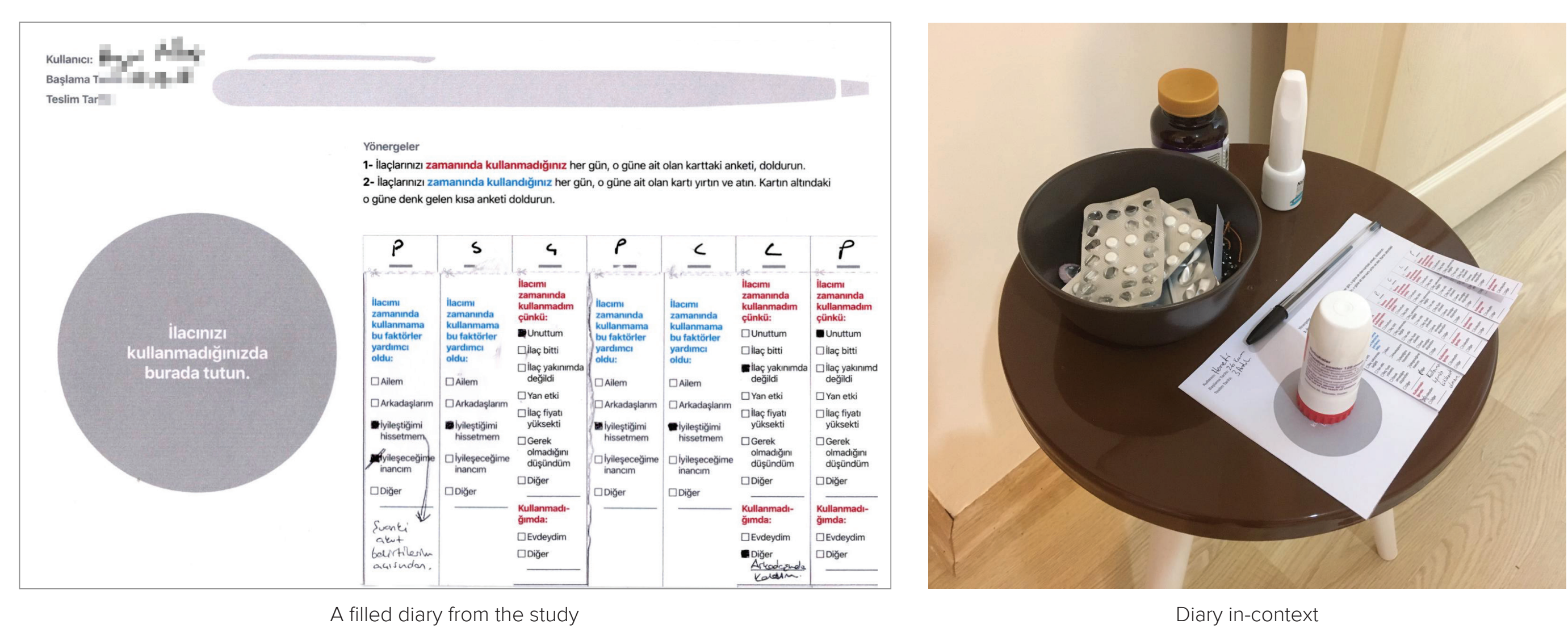
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Abstract

As famously stated by former US Surgeon General C. Everett Koop, "Drugs don't work in patients that don't take them". Medication non-adherence is a huge and increasing problem in the medical industry, associated with almost 200.000 deaths and an excess cost of €80-125 billion only in the European Union[1]. Among the most non-adherent patients, asthma patients stand out because of not only they face regular challenges of being adherent, they are supposed to use inconvenient inhalers instead of regular pills. As stated by the Guide for Asthma Management and Prevention, 80% of asthma patients do not use their inhalers correctly or regularly[2]. Although there are some studies focusing on the reasons of medication non-adherence[3 4 5], they mostly identify generic reasons and do not dive into patient's detailed experience and journey. This study aims to understand the emotional and cognitive experience of asthma patients throughout different stages of the disease and perceive the motivations and challenges of taking medication correctly and on time. Research was conducted with a semi-structured interview utilizing UX curve[6] method, followed by a week-long diary study to deeply understand patients' cognitive and emotional models. Overall findings show that participants have distinct motivations and barriers on medication adherence and have developed their way of living with the disease, although it is not always desirable.

Study

The research was conducted on 4 participants in three steps. First, semi-structured interviews were conducted with the participants using UX curve, a research method which assist users to retrospectively report how and why their long-term experience with the disease and medication usage changed, by giving them an empty two-dimensional graph area for briefly describing their positive and negative experience while drawing a curve[6]. Second, a week-long diary study was done with participants who are actively using their medicine (n=2) to learn more about their daily used techniques or barriers on inhaler usage. The diary was designed as a tear-off card which had quick questionnaires for each day. If the participants took their medicine that day, they were prompted to tear off that day from the card, which reveals a questionnaire underneath related to participants' motivations on taking their medicine that day. If the participants skipped their medicine that day, they were prompted to fill the quick questionnaire on that day of the card related to the reasons of missing that day's dose. Finally, a post-interview was conducted with participants who have successfully finished the diary study to uncover the reasons of medication non-adherence and their personal techniques.

Methodological Steps

UX Curve example

A filled diary from the study

Diary in-context

User Experience Model

- Participant 1
- Participant 2
- Participant 3
- Participant 4

POSITIVE — NEUTRAL — NEGATIVE

TREATMENT PLAN

Adherence Techniques

Putting medicine on eye-sight

"It was easier when I lived in a dormitory. There was only one desk, and I knew I will definitely look there every morning."

Adopting medicine into daily routine

"I put my inhaler next to my toothbrush. I know I will brush my teeth every morning and night, so I never forget using my inhaler."

Family support

"My mother used to remind me everyday before breakfast. After starting high school, I left home early, so I usually forgot taking medicine."

Putting all medicine together

"I always carried a small fabric bag that I kept all my medicine in. It was convenient especially when I did not have a routine life."

DROP-OUT

Reasons to Miss a Dose

Not seeing results / effects promptly

"When I miss a dose or two, my asthma does not feel any different, so I figured it is okay to miss now and then."

Running out of drugs

"I usually run out of my meds before I get refills. I do not use meds for 2-3 days to a week in those refill times.

Breaking the routine

"I usually forget taking my medicine when I go to vacation, or stay at a friends house."

"I forgot to use my inhaler because I did not sleep that night."

Reasons to Drop-out

Side Effects

"Inhalers made me gain weight, so I avoid them as much as I can."

Feeling "healed"

"I felt that I am cured, did not show any symptoms for a while. So I stopped using my inhalers."

> How might we help patients stay on track with their treatments when they break their routines?

> How might we communicate that asthma care needs daily attention even though it feels like it is cured?

DIAGNOSIS

A Terrible Experience

"I had to be hospitalized for a month when I was in 4th grade. It was a very scary experience for a kid."

"I used to hit walls to wake up my parents when I had trouble breathing when I was a kid."

"When I was 40 days old, they realized I couldn't breathe because my face turned purple."

EXACERBATION!

"After I stopped using my inhalers, I experienced an exacerbation in the middle of an exercise. I was hospitalized for a month."

COMPROMISE

Experienced the consequences

"I take my medication on time, because I have experienced an asthma attack. That is my sole motivation."

> How might we help users empathize with their future worsened selves, so that they take their illness more seriously without experiencing an exacerbation?

Accepting the disease

"For the last 5 years, I accepted asthma as a part of me. I realized that it is an illness a lot of other people have, which makes me feel normal."

"I know asthma will never be cured. However I know I can control it and live a healthy life, therefore I use my medicine."

Change of lifestyle

"I stopped being as much active as before. I don't play soccer a lot anymore. Therefore I don't have to use my meds regularly."

"I moved to another city. I couldn't live in my hometown because of high temperature and humidity."

Becoming "my own doctor"

"I know how my disease works. I do not need to go see a doctor that often. I know which meds to take when my condition gets worse, or when I should stop using meds."

Feeling "dependent"

"I don't like that I am dependent to medicine. It makes me feel weak and needy."

Social exclusion

"I feel like I grew in a bubble. Today still, I am unable to attend a lot of social activities to avoid smoke, cold weather or allergens."

> How might we develop "asthma pride", helping patients overcome their insecurities related to their sense of being dependent and excluded?

Findings

Findings of the study show that if participants experienced a severe shortness of breath (exacerbation, they are much better at sticking to their treatment plan. That is mainly because they can easily relate to what will happen when they do not adhere. On the other hand, it is really easy to drop out for others because the medication do not show any short term improvement or feedback. For that reason, when missed once or twice, nothing seems to really happen and adherence behavior slowly fades away. Some participants mentioned that they were "healed" therefore they do not need to use their medication anymore. However, asthma, similar to all other chronic diseases, needs to be kept under control with daily medication even though it might not show any symptoms. The data from the diaries show that mostly adherent participants missed some doses when their routine is changed. These situations included "staying over a friend's house" and "pulling an all nighter". Some participants mentioned they felt socially excluded because of the precautions they need to take, like avoiding smoke or cold weather. They reported feeling bad because they felt that they are dependent to inhalers. One participant even mentioned dropping out of treatment after feeling flawed because of this dependency as a constant reminder of their illness.

Reflections

Combining UX curve with a diary study was very helpful in terms of understanding participants' both long term experiences and their daily challenges & motivations. Combining that information gave a comprehensive sense of their experience. The design of the diary was very crucial in the study. It needed to be as invisible as possible so that participants do not remember taking their medicines thanks to it, otherwise the data aimed to be gathered would be skewed. Moreover, filling the diary should have been as little time consuming as possible so that participants wouldn't get demotivated during the week-long process.

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